

A helping hand

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The girl with the page-boy haircut and impish smile shows off her dancing skills as her father applauds wildly.

But a few minutes later, her entire body spasms, as she suffers a seizure. Her father holds her in his arms.



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Emily Santana, 4, of Lodi, seated with her father, Tito, and Jane A. Grinch, left, board of trustee president, and Diana DiGirolamo, executive director.

It's a typical morning in the life of 4-year-old Emily Santana, a passionate fan of rock music and Mr. Potato Head, and the victim of a brain tumor, stroke and recurrent seizures.

At the advice of Emily's doctors, her father, Tito Santana, scheduled what some medical experts dubbed lifesaving surgery for Emily's epilepsy. But the insurance company refused to pay, and the surgery was canceled three days before it was to be performed at Beth Israel Medical Center in Manhattan.

Santana, who lives in Lodi, was distraught. He turned to the Hackensack-based Community Resource Council, a crisis intervention center. Diana DiGirolamo, the group's executive director, feverishly worked the phones and fax machines and sent letter after letter until she secured new insurance coverage for Emily's procedure.

Thanks to her efforts, Emily is having the surgery.

Santana says he's indebted to the council, which also raised money for him to buy furniture, appliances and a used car after he sold the family's belongings three years ago to cover Emily's medical expenses.

"She's like an angel," Santana said of DiGirolamo, who smiled modestly. "Our policy is to help as much as we can to facilitate solutions," she responded. "We handle the most desperate cases when nobody else can help."

Doctors discovered Emily's two brain tumors when she was 6 months old. She underwent surgery for their removal when she was 14 months old and suffered a stroke, which left her partially paralyzed. Ever since, she has been plagued by seizures, often as many as 30 a day, Santana said.

Santana, whose wife, Tania, suffered emotional difficulties after Emily's diagnosis, works through the night delivering bread so he can care for Emily during the day. He has gone from doctor to doctor, searching for the panacea for his daughter's ailments.

"I will never give up," he said.

Emily's surgery will hopefully do what medication has been unable to accomplish: cure her epilepsy, Santana said.

"We will implant electrodes in Emily's brain to discover where the seizures are coming from down to the precise millimeter," said Dr. Steven Wolf, director of Pediatric Epilepsy at Beth Israel Medical Center in Manhattan. After doctors map out the location, they will remove the scar tissue, Wolf said.

Wolf praised the Santanas for their tenacity.

"I give them credit for not putting up with the status quo. They keep questioning and saying, 'Isn't there something else I can do for my child?'"

"They are heroes because so many families get frustrated, but [the Santanas] don't take no for an answer," Wolf said.

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